

Family Partnership Newsletter: Fall 2019



Missouri Department of Health and Senior Services

health.mo.gov/familypartnership

SHCN FAMILY PARTNERSHIP

- * *Updates from your Family Partners*
- * *For Families by Families*

Welcome to the first Missouri Family Partner Newsletter! In this edition, you will learn about the exciting launch of the medical home initiative, meet the Family Partners, and read real life stories about Missouri families starting with your Family Partners submissions called Caring Corner.

This newsletter is designed for families by families and we encourage you to submit your story to FamilyPartnership@health.mo.gov so we may share your journey in an upcoming newsletter. Also, be on the lookout for information about the 2020 Family Partnership Parent and Caregiver Retreat. Date and location will be announced in early 2020.

Missouri Medical Home Initiative

A medical home is not a building—it is a family-centered approach to comprehensive care for your child. Through this partnership, you work with health care experts to find and access the medical and non-medical services your child needs. Your medical home care team may include doctors and nurses, therapists, dentists, pharmacists, community health workers, school staff, friends, neighbors, and anyone else who cares for your child.

Receiving care through a medical home can improve your child's health and make life easier for your family.

Components of a medical home are:

Accessible - Care is provided for your child in your community 24 hours a day, 7 days a week.

Family-Centered - You are recognized as an expert for your child and a valued member of the care team.

Continuous - The same pediatric health care professionals care for your child from infancy until it's time to transition to adult care.

Comprehensive - Your child's care includes checkups, sick visits, therapy, and specialty care. Your family is connected to support and educational services.

Coordinated - The care team works with multiple providers to develop a care plan, book appointments, handle referrals, and provide access to resources.

Compassionate - All members of the care team are genuinely concerned about the overall well-being of your child and family.

Culturally Effective - Services are delivered in your preferred language and the care team respects your family's cultural and religious beliefs.

Meet the Family Partners

Northwest Family Partner Karese Love

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My name is Karese Love. I am the Northwest Family Partner for the Bureau of Special Health Care Needs. Prior to moving to Kansas City, Missouri in 2008, I diligently worked in the Early Childhood Education (ECE) field for six years. In January of 2012, my family welcomed a daughter, born with Hypoplastic Left-Heart Syndrome (HLHS). During my time as a stay at home mother, I attended the University of Missouri to further my education. I joined Family Partnership in February of 2017 and have enjoyed being involved with supporting families. Recently, I have also become a member of the Missouri Parent Advisory Council. I hope to continue to broaden my knowledge of special health care needs practices, while aiding families with peer support and resources.

Family Partner for Deaf and Hard of Hearing Lydia Sergeant

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My name is Lydia Sergeant and I joined the Family Partnership in November 2017. I was hired to work with families who have children that have been identified as deaf or hard of hearing. I have been married to my husband, David, since 2002. I have 2 daughters. The oldest, Ella, was born with a rare genetic syndrome, Kleeftstra Syndrome. One piece of this syndrome is often hearing loss of some kind. Ella was diagnosed as hard of hearing at the age of 2 ½. I have a passion to learn as much as I can about the deaf/hard of hearing world and how that can help my family as well as other families. I am always looking for new resources and webinars. I am very excited to be a part of the Family Partnership and to work alongside of families.

Southwest Family Partner Camelia Hallahan

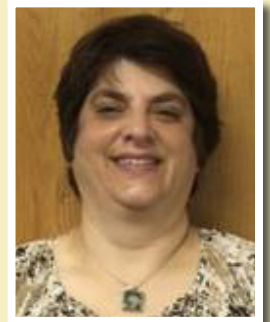
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My name is Camelia Hallahan. I am the Family Partner for the Southwest Region for the Bureau of Special Health Care Needs. I live in the small town of Vienna, MO. I've been married to my adventurous husband, Jake, for 10 years. Our daughter, Karlee, just turned 21. She has a rare skin disease known as Recessive Dystrophic Epidermolysis Bullosa (RDEB). We also have two sons, Tyler (9), and Tanner (7). My hobbies include gardening, camping, going to the river, and spending lots of time with my family.

Northeast Family Partner Pat Fox

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My name is Pat Fox. I am married and have three children: Mikaela, Branson, and Patrick. My youngest son, Patrick, was diagnosed at six months of age as having a rare genetic disorder, T8M. I have been a Family Partner since 2014. I have served on the Missouri State Rehab Advisory Council for the Blind, I have been an instructor for Ability Awareness with the Delta Gamma Center for Visually Impaired Children, and advocated for my local school district to become more all abilities friendly. I am the Vice President of the St. Louis Family Support and Respite Coalition. I participate in workshops at St. Louis ARC, I am a partner with the Patient and Family Center Care and the Palliative Care Advisory. I also belong to Heartland Genetics and work with Lead Colln, and St. Louis Generate Healthy Families.

Meet the Family Partners continued...

Family Partner for Deaf and Hard of Hearing Bridget Wildschuetz

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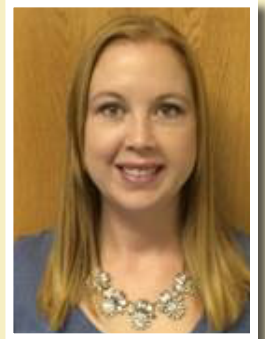
My name is Bridget Wildschuetz. I live in St. Louis. I joined the Family Partnership in January of 2019. My role involves helping families with children who are deaf or hard of hearing. I am married and a mother of two children, Faith and Graeme. Faith was born with a rare gene mutation called SOX2 anophthalmia. She is completely blind and has bilateral mild-moderate sensorineural hearing loss. She is medically complex and has severe global developmental delays. She has an amazing smile and is the most hard working and determined girl I've ever known! She loves music and swimming. My son, Graeme, is a great younger brother. He is very active and loves watching and playing sports. This is my nineteenth year in the education field. I taught middle school and high school health and physical education for almost ten years before Faith was born. Then, I transitioned to working part-time so I could take care of all of Faith's extra needs. I currently teach developmental student success courses part-time at a local community college and work as a Family Partner part-time. I am eager to share the knowledge and resources I have acquired throughout my family's journey with other families.



Southeast Family Partner Sheree Pursley

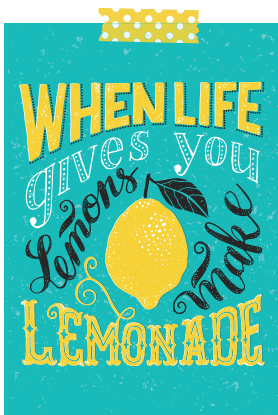
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My name is Sheree Pursley. I have been married to Greg Pursley for 14 years. Together, we have two amazing children: Evee-Kay (13) and Izaac (11). The day Izaac was born, he was diagnosed with Achondroplasia, a form of Dwarfism. At first, we were adjusting to physical and stature differences but at three months old he started requiring oxygen, a pulse ox, and an apnea monitor full time. The challenges we faced over the next few years was unimaginable. At seven months old, Izaac got pneumonia and had to get a trach and was full time vent dependent. Our family had to work together seamlessly with the help of medical professionals, equipment suppliers, and various state agencies to name a few. All of this is being done while trying to keep a marriage healthy and a daughter from feeling neglected. We have all learned a tremendous amount about determination through our faith. By working with each other as a team we have made amazing progress and Izaac will be in 6th grade this fall.



"The Family Partnership provided an opportunity to talk with other families and learn how to manage the unique challenges that we face every day."





The Family Partnership Parent & Caregiver Retreat was held September 6-7, 2019 at The Lodge of Four Seasons, Lake Ozark, MO. The Retreat provides an opportunity for families to network with one another, discover resources to assist their family, enrich their leadership and partnering skills and plan a vision for their family's future. The theme of this year's Retreat was "When Life Gives You Lemons, Make Lemonade." We all encounter situations, the lemons, in our day-to-day lives and how do we turn them into something positive, like lemonade? This was the focus of the interactive networking session on Friday evening. In addition, the Family Partners would like to share a few of the quotes from the evaluations collected from families at the end of the Retreat.

- MANY FOLKS REACHED OUT TO ME TO PROVIDE ME WITH INFORMATION ABOUT MY SITUATION, FOR THAT I AM TRULY GRATEFUL.
- THERE ARE A LOT OF PEOPLE OUT THERE WHO SHARE OUR STRUGGLES & CAN IDENTIFY WITH OUR SITUATION.
- THINGS AREN'T HORRIBLE, OUR SITUATION WHILE NOT DESIRABLE, ISN'T THE END OF THE WORLD.
- LIVING VS. BEING ALIVE, IMPORTANT TO FIND MENTORS WITH SIMILAR LIFE EXPERIENCES TO HELP ANTICIPATE YOUR FUTURE, APPS FOR SEQUENCING-CAN PLAN & CAN WORK.



- IT'S GIVEN ME THE CHANCE TO RECHARGE, BE AROUND PEOPLE WHO ARE GOING THROUGH THE SAME THING AND NOT BE JUDGED.
- MORE AWARE OF HELP AVAILABLE. MORE AWARE OF WHAT OTHERS ARE GAINING THROUGH RAISING SPECIAL NEEDS CHILDREN.
- THE FEELING OF KNOWING WE ARE NOT ALONE.



"2019 CC Rhythm"

- REALLY WELL DONE. I APPRECIATE MEETING SO MANY DIFFERENT PEOPLE AND HEARING ABOUT SO MANY DIFFERENT OPPORTUNITIES.
- FOR THE FIRST TIME IN THE 4 YEARS OF MY CHILDS LIFE I MET SOMEONE WHO'S CHILD HAS A VERY SIMILAR RARE DISABILITY. THANK YOU.
- HAD A WONDERFUL TIME. GOT TO RELAX AND LEARN ABOUT ALL THE POSSIBILITIES OF LIFE CHANGING CHOICES TO MAKE LIFE EASIER WITH HAVING A DISABLED CHILD.
- THIS IS SUCH A GREAT EXPERIENCE FOR MY HUSBAND AND I. IT HELPS TO HAVE FINANCIAL HELP WHILE DOING THIS RETREAT, OTHERWISE WE WOULD NOT BE ABLE TO ATTEND. WE GET TO CONNECT WITH OTHER PARENTS AND LEARN NEW RESOURCES.



- THE SCHEDULING OF THIS RETREAT IS GREAT. SO MANY TIMES RETREATS ARE EXHAUSTING, RUNNING FROM CLASS TO CLASS, YOU GIVE PLENTY OF TIME IN BETWEEN EVENTS SO PEOPLE CAN HAVE REST PERIODS & FEEL REFRESHED. ALSO, THE FREEDOM TO PARTICIPATE (OR NOT PARTICIPATE) IN THE VARIOUS SESSIONS IS GOOD. SOMETIMES THESE PARENTS FIRST NEED A BREAK IN A BEAUTIFUL PLACE. THANKS!! AND IT'S GREAT THAT ALL THE LEADERS IN THIS ARE PARENTS OF SPECIAL NEEDS CHILDREN & KNOW WHERE ALL THE 'PARTICIPANTS' ARE COMING FROM. SO OFTEN LEADERS HAVEN'T BEEN THERE AND DON'T HAVE A CLUE WHAT THE PARTICIPANTS ARE GOING THROUGH. GREAT RETREAT! KEEP UP THE GOOD WORK!
- THE RETREAT IS AN EXCELLENT OPPORTUNITY TO NETWORK AND BECOME MORE SOCIALLY INVOLVED.
- I ENJOY MANY MANY THINGS ABOUT THIS EVENT. BY FAR HAVING TIME ALONE WITH MY SPOUSE IS SO WONDERFUL. WE ARE ABLE TO PLAN, SET GOALS AND DEBRIEF ABOUT OUR LIFE. IT IS ALSO SO GREAT TO UNDERSTAND I AM NOT ALONE IN MY CHALLENGES. THE TOPICS, SPEAKERS, EXHIBITORS ARE ALSO GREAT.
- WAS A LOT OF FUN. WAS THRILLED TO GET TO MEET NEW PEOPLE AND MAKE SOME NEW CONTACTS.

Caring Corner...

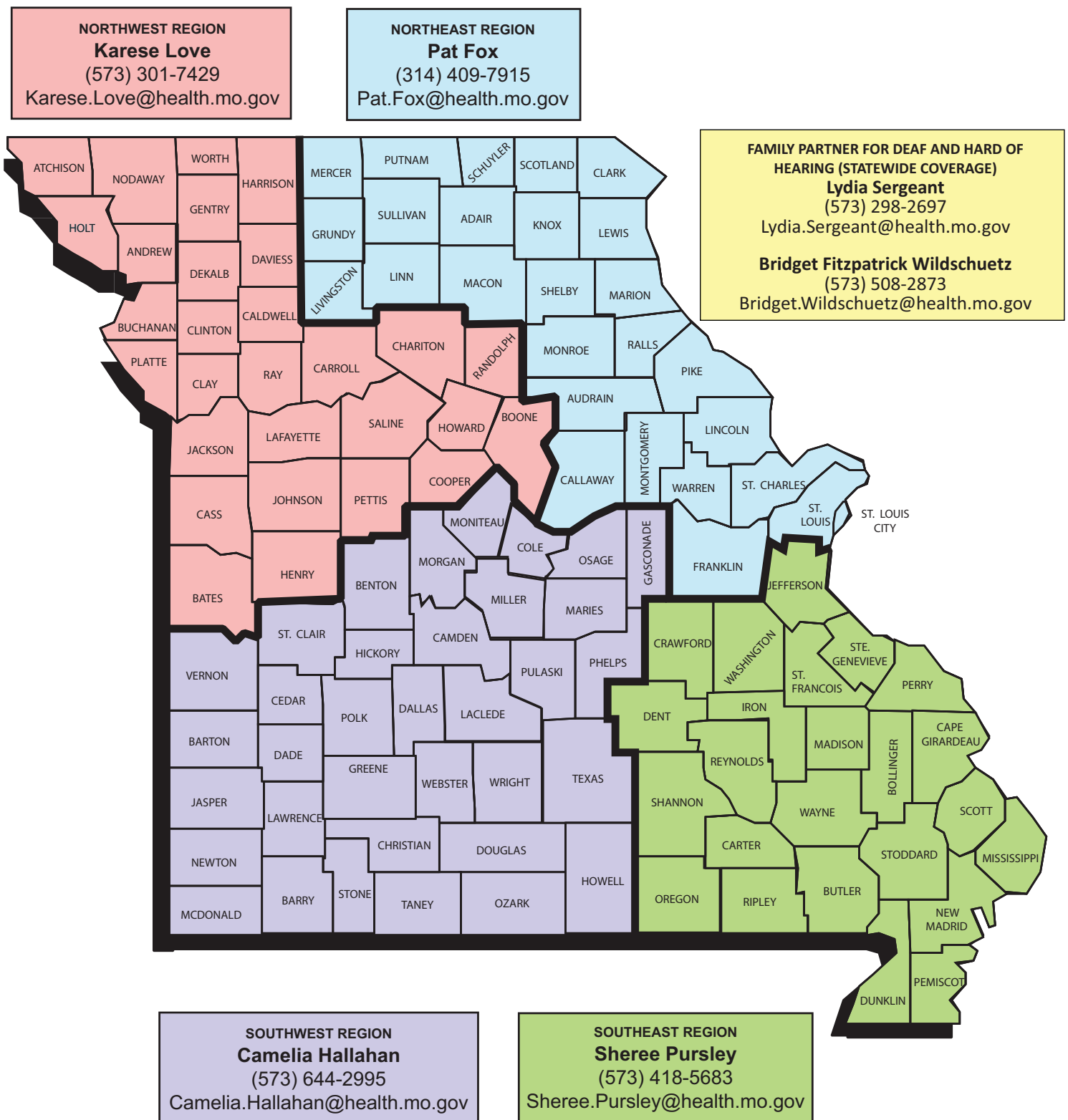
- My son, Izaac, just finished up his second season of Noon Optimist basketball with his typically functioning peers. His favorite part of his whole season was during the last game when he got a foul. He was so excited to be like everyone else that he double checked with the officials to make sure that they got his number correct when they recorded the foul!

- My son, Patrick, was born with a rare genetic disorder, Trisomy 8M. He was not able to eat orally and was tube fed. Missing out on the fun of getting candy on Halloween and his birthday, the fire department would give Patrick a ride in the firetruck. He loved the firemen and firetrucks, so this was better than anything available to eat—at least Patrick thought so. The moral of this story is that even though our children might miss out on something that other children take for granted, there is usually something better for our children, if you just think outside the box.

- Faith started participating in local running races with an organization called Ainsley's Angels. She rides in a special running wheelchair called a chariot. She loves the movement and being out on the course hearing people cheering for her. It has been a great opportunity for her to be included in the community. We are looking forward to upcoming races.

- Ella is non-verbal, but has been learning sign language. Her favorite toy to play with is a ball (we have a lot!). Recently we went to Branson for a weekend getaway. While there, we went to a toy store to look around. She saw a large bin of balls. She looked at her dad and signed "more". He signed back "no". She continued to sign to him and finally signed over and over "More ball, yes, please, now". Needless to say, we were very impressed with her communication and she came home with a new ball.

FAMILY PARTNER CONTACT INFORMATION



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